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A stitch in time saves nine: perceptions about colorectal cancer screening after a non-cancer colonoscopy result. Qualitative study.

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## **Abstract**

**Objectives:** To explore perceptions of colorectal cancer (CRC) screening among participants who have experienced a 'false alarm' for CRC, and to explore perceptions about the relevance of screening for themselves or others.

**Methods:** Semi-structured interviews with screening participants who had participated in the Danish CRC screening program and experienced a 'false alarm' for colorectal cancer. A thematic analysis was performed, based on an interpretive tradition of ethnography.

**Results:** Perceptions about CRC screening after a non-cancer colonoscopy result were characterized by trust in the colonoscopy result showing no CRC, and satisfaction with the screening offer despite the risk for 'false alarm'. The patient-involving behavior of the healthcare professionals during the examination was for most participants a cornerstone for trusting the validity of the colonoscopy result showing no CRC. Strong notions about perceived obligation to participate in screening were common.

**Conclusions:** Prominent themes were trust in the result, satisfaction with the procedure, and moral obligations to participate both for themselves and for others.

**Practice implications:** Information to future invitees after a 'false alarm' experience could build on peoples' trust in the validity of a previous non-cancer result and should underscore the importance of subsequent screening even after a 'false alarm' for cancer.

**Keywords:** health services research; population-based cancer screening; colorectal cancer; fecal testing; qualitative research; patient trust.

## **1. Introduction**

Colorectal cancer (CRC) is the second most frequent cause of cancer-related deaths in men and third commonest in women in developed countries (1). It is treatable, especially if detected at an early stage (2). Population-based screening programs for CRC have been implemented in many countries using fecal occult blood testing (FOBT), and the most commonly used test is the fecal immunochemical test (FIT) which is more user friendly and has a higher sensitivity and specificity compared with the guaiac fecal occult blood test (gFOBT) (3, 4). High screening uptake and adherence to follow-up colonoscopy are necessary to achieve public health benefits (5-7). However, screening also involves risks for 'false alarm' for the individual participant if the FOBT detects blood in the stool, indicating a risk of CRC, and it is followed by a diagnostic colonoscopy which does not detect CRC. This might cause residual uncertainty and distress in some individuals, but results about distress related to CRC screening participation are inconsistent, suggesting no clinically relevant distress in most participants (8-19). Some studies indicate that feelings of trust and moral obligation are drivers of participants' intentions to be screened (20-23). There is, however, little research on how participants perceive CRC screening when they have experienced a 'false alarm' for CRC, i.e. a positive FOBT followed by a non-cancer colonoscopy result, or how important they perceive future screening participation, either for themselves or others. The aim of this study was to explore perceptions of CRC screening among participants who have experienced a 'false alarm' for CRC, and to explore perceptions about the relevance of screening for themselves or others.

## **2. Methods**

### *2.1 Setting*

Denmark has the highest age-standardized CRC incidence rate in men (69.2 per 100,000), and the second-highest age-standardized incidence rate in women (53.4 per 100,000) among the Northern European countries (24). The CRC screening program was implemented in 2014 for residents aged 50-74 years and uses FIT self-sample kits, sent directly to the home, with the invitation to participate in the screening program. The Danish CRC screening program has a participation rate of 65%, and 7% of participants receive a positive FIT result and an appointment for follow-up colonoscopy. Ninety-two percent attend for colonoscopy of whom 6% have CRC, 52% have polyps

removed, and 42% have no abnormalities of the colon (25). As for most other Danish healthcare services, participation in population-based cancer screening including possible subsequent investigation or treatment is free of charge (26).

## *2.2 Design and participants*

This was a qualitative interview study with men and women who had participated in the Danish CRC screening program. They had received a positive FIT result, attended a follow-up colonoscopy, and received a result which was negative for CRC (i.e. polyps, or no abnormalities). Recruitment took place through the call center of the regional screening provider (27). A secretary identified eligible participants when they called to change the pre-booked appointment for colonoscopy, according to a maximum variation sampling strategy including gender, age below and above 65 years, marital status, and geography (urban/rural) (28).

All interview participants were interviewed before the colonoscopy by an experienced interviewer (PK) about their emotional responses to a positive FIT result, as described elsewhere (29). At the end of these interviews, they were asked for permission to contact them again for a follow-up interview about the whole screening experience. This study reports results from the follow-up interviews.

## *2.3 Data and analysis*

A funnel-structured research cycle of ongoing questions, data **production**, and analysis was adopted for an explanatory approach based on an interpretive tradition of ethnography. **The interpretation begins with the formulation of the research question and continues through the data production, and it is not an independent, separate phase after the interviews have taken place (30). The approach was constructivist with an emphasis on phenomenology, aiming to explore how people make sense of their own experiences in a specific context (31).**

A semi-structured interview guide (Appendix 1) was designed to cover experiences with the follow-up colonoscopy at the hospital, the result of the colonoscopy, perceptions of benefits or harms of screening, emotional 'journey' during the whole period from invitation to screening, perceptions about the relevance of screening, and expectations regarding future participation in screening with FIT (32). The interviews were performed in the participants' own homes by PK 4-6

weeks after colonoscopy to ensure study participants had received the result from the hospital. The interviews were digitally recorded and transcribed verbatim by PK and a secretary. Before each interview, the transcription of the previous interview was read carefully and questions emerging from the data were added to the dynamic interview guide. Each transcript was read and reread several times by PK who conducted the initial coding **and meaning condensation** and presented it for discussion with the co-authors to establish preliminary themes. Differences and similarities were discussed among the authors to generate new insights and narrow down the focus of the themes. When no substantially new data were generated in the interviews, the credibility of the chosen themes were validated by performing telephone interviews with other participants in the target group recruited in the same way as the study participants for the face-to-face interviews, in order to assess the level of information power (33). When the interpretations were agreed upon by the authors, the analysis was crystallized to a coherent set of themes **and existing literature about people's experiences in comparable contexts were selected to provide a meaningful contextualization of the findings.**

#### *2.4 Ethics*

The study followed the principles from the Statements on Ethics of the American Anthropological Association (34). It was approved by the Danish Data Protection Agency (j. no. 2012-58-0006/1-16-02-187-15) and did not require further ethical approval in accordance with Danish legislation (Act on Research Ethics Review of Health Research Projects) (35). Written consent was obtained from all study participants.

### 3. Results

Thirty individuals were approached via the call center, of whom three did not wish to participate and for five it was not possible to get an interview appointment. All 22 individuals accepting to be interviewed before colonoscopy were also available for this follow-up interview after colonoscopy (29). Information power was continuously assessed in the data collection and analytic process, and after sixteen semi-structured face-to-face interviews it was decided to perform telephone interviews with the remaining six individuals to substantiate and confirm the analysis (33). Table 1 shows characteristics of all participants and how they were interviewed. Where possible, spouses participated in the face-to-face interviews. Ten out of 16 face-to-face interviewed participants had polyps removed during the colonoscopy (14 out of 22 participants in total). We identified and explored three themes in the accounts: care, involvement, and trust; risk and satisfaction; and moral obligation to participate in screening.

#### 3.1 *"Nothing could escape": care, involvement, and trust*

The colonoscopy was described by most participants as a physically unpleasant procedure (bowel preparation and the investigation itself), but the overall experience was characterized by relief about the result and trust in the skills of the healthcare professionals (HCPs) performing the colonoscopy. Many participants in our study attached great importance to the caring behavior of the HCPs and described them as trust-promoting, empathetic, and attentive to the participant's needs and questions. They appreciated the effort the HCPs took to make the examination as comfortable and pleasant as possible. Judith, 68 years old, had had a colonoscopy in the past due to bowel symptoms and polyps but she had never been diagnosed with cancer, and she was worried about the colonoscopy itself and the result. She knew from the previous colonoscopies that she could get 'something into the hand', meaning a sedation to make her fall asleep during the procedure. The HCP followed her wish for full sedation, and during the interview she stressed how grateful she was about the care and understanding from the HCPs. She said:

Judith: They have been so sweet to me. They listened to my worries. They took me by the hand.

Right after the procedure the doctor told her there were no signs of cancer, and no polyps. She and many other participants had not told family or friends about the positive FIT result, because

they did not want to cause unnecessary worry (29). The colonoscopy, on the contrary, was perceived as a certain result, an 'acquittal', and many participants reported they had told their family and friends about the procedure after they had been 'acquitted' by the great and reassuring news that there was no cancer.

Most participants were awake during the colonoscopy, following the recommendation to use as little sedation as possible. They reported they could see live images of their own bowels on a display screen during the examination, and talk to the HCPs while looking at the screen. They stressed the importance of being involved during the examination, including when the HCPs explained real-time about their findings during the removal of the colonoscope. Connie, 74, reported the HCP talked her through the procedure, and she could see for herself what was happening inside her:

Connie: It was such a positive experience. They told me during the whole procedure what they saw, and they blew up and removed some tiny little polyps.

She and others underscored their trust in the effectiveness of the medical technology – the colonoscopy – to detect cancer, in contrast to the FIT which they knew can only detect blood. The trust in the technology was supported by its visual character. William, 69, who had no polyps or other abnormalities, expressed his trust in the validity of the colonoscopy result this way:

William: I must say that the technology is very advanced. I could follow the whole thing on a screen while the doctor told me what it was. There were many pairs of eyes looking at that screen! The instrument went in all the nooks and crannies and sometimes I needed help to turn my body so he could operate the instrument. He almost pulled it through and scratched all surfaces in the corners. Nothing could escape.

The immediate sharing of information during the procedure was highly valued, and it supported a feeling of being 'taken seriously' and treated as a partner in an otherwise highly asymmetrical situation.

### 3.2 "...it is good to get a thorough examination": risk and satisfaction



Some participants underscored that every thorough health examination may involve a risk for 'false alarm'. Positive FIT was regarded a 'reasonable suspicion', and a risk for 'false alarm' was worth taking. William put it this way:

William: When you think about getting a health check...Every single time you get a medical examination there is a risk of finding something. There is always something to find, it is just a matter of how thorough the doctor is. It is the same thing here, but with screening, there is a reasonable suspicion

His statement expressed an act of balancing risk for 'false alarm' and risk of undetected cancer. He and other participants stated that a thorough examination is a benefit, and if there is the slightest indication or risk of serious disease, the offer of an examination should be embraced. Many participants looked back and reasoned that participation in FIT-based screening was the right choice for them. Michael, 58, had no polyps and stated that:

Michael: Even though it may be false alarm which it is in this case, it is good to get a thorough examination

He had suffered from hemorrhoids in the past and had polyps removed during a previous colonoscopy, and he thought the blood might stem from them. However, the colonoscopy showed no signs of either. He expressed satisfaction with the offer of a thorough examination, just to be sure, trusting in the final result showing no cancer or polyps.

Mary, 74, also had a long history of bowel symptoms, blood in the stool, hemorrhoids, and polyps, and she had undergone colonoscopy before but no cancer had previously been detected. This time was no different, and she expressed satisfaction with the screening procedure:

Mary: I think it is such a comfort to get screened and to be told that there is no cancer at all. I can only be content with this screening procedure

Most participants expressed satisfaction with the screening procedure including the removal of polyps. Christine, 70, expressed it this way:

Christine: It was good to get them removed and be told that there is no cancer. I think it is good. It is, really. If I should choose between screening and no screening, I would choose screening. I think it is good that the offer is there

For Mary, Christine and others, the positive FIT had served a purpose of getting a thorough examination of an essential part of their body which they cannot inspect by themselves, and the colonoscopy result was a confirmation or restoration of good health.

Expressions of satisfaction with screening procedures and gratitude towards screening offers were common among the participants. Some participants referred to other times they had participated in screening programs with a positive result, and used the examples to underpin the benefits of screening. When Karen, now 60, entered the screening program for breast cancer at the age of 50, a lump in her breast was found and removed. Her experience with a screening-detected breast cancer, made her reason that the risk for 'false alarm' outweighs the risk of undetected cancer.

Karen: Ten years ago a lump was removed from my breast and you know what, it was malignant. I was screened and they found it. I can only be grateful for screening. I couldn't feel it or anything, but they found it when I was screened, and you know what, it could have grown if they hadn't found it. I can only be grateful for screening

For some participants, knowing about other screening programs than the CRC screening program could trigger a sense of 'familiarity' with screening. Michael expressed it this way:

Michael: My wife has participated in screening since forever so I know about screening. It is not a stranger to me. There is nothing to lose by participating.

He and the other men in the study had not participated in population-based cancer screening before because the other implemented cancer programs are for women only (screening for breast cancer and cervical cancer). In his view screening was a win-win situation: an all-clear for cancer is great news; in case of a detected cancer, screening has served its purpose.

### *3.3 "It is an offer you should accept": moral obligation to participate in screening*

Most participants emphasized individual freedom to choose how to live (e.g. to smoke or eat unhealthy food) but they also stressed the importance of individual responsibility to stay healthy, and participating in screening was one means to stay healthy. Frank, 67, felt strongly about a perceived obligation to participate in screening.

Frank: To me there is no alternative to screening. I think it is outright stupid when people say they won't participate in screening. It is always easier to tackle things earlier

His statement referred to common aphorisms for prevention of disease, such as 'a stitch in time saves nine' or 'better safe than sorry', to underscore that efforts to prevent or detect disease in an early stage are preferable compared to taking a chance on one's health.

Some participants also emphasized a social obligation towards one's family to stay healthy by participating in screening. By participation, CRC could be detected and future incidents could be avoided which would ultimately protect the well-being of the family. Thomas, 58, put it this way:

Thomas: Screening is just something you should do. It is no fun but you should do it for your family's sake. This is a priority of society. Finally, when there is a screening offer for men, we should jump at the offer

Thomas subscribed to the notion that screening participation is a social obligation towards one's family, and viewed society as the guarantor for the relevance and quality of the offer. Both male and female participants in this study were also enthusiastic about the fact that for the first time in Denmark, a population-based cancer screening program is offered to both men and women. Some participants told stories about men they knew first hand or men they had heard of who 'refused' to participate in screening, and they pondered their refusal, speculating that men in general might be less motivated to take care of their own health – or less able – than their female counterparts. Joan, 71, said:

Joan: Finally, there's an offer for men! They are not that good at taking care of themselves. Hopefully they'll know how to do it

A prominent concern among participants was about resources. Screening participation was often voiced as a reasonable way to use finite resources in the health care system, while non-participation was by some perceived as a waste of money which had already been paid by active members of society. Jane, 61, emphasized individual freedom to decline screening but at the same time she argued for a moral obligation to participate:

Jane: It is up to you to decide whether you want to be screened, but I think it is silly if you don't participate. We all pay for this in the end. In fact I think you have no right to say no

Frank also pointed to the tension between individual freedom and moral obligation, but he was sure that he would participate again if he was invited:

Frank: Of course I will say yes if they call me in. And yes, I will recommend others to take care of their health but there is no obligation. It is an offer you should accept. You can just say no if you don't want to be examined. I just think it is a benefit because we live in a society where it is better to prevent than to cure disease. I think it costs less for society that way

All participants said they expected to get screened in the future and they would recommend others to participate too.

## **4. Discussion and conclusion**

### *4.1 Discussion*

The most prominent themes in the accounts of participants with a positive FIT result and a follow-up colonoscopy which was negative for CRC were care, involvement, and trust; risk and satisfaction; and moral obligation to participate in screening.

The experiences were characterized by trust in the professional skills of the HCP performing the colonoscopy. The patient involving behavior of the HCPs (listening to worries, talking-through the colonoscopy procedure, looking together at the display screen) was for most participants a cornerstone for trusting the validity of the colonoscopy result showing no CRC. For most participants, being fully awake during the procedure supported their sense of having seen with their own eyes that there were (in some cases polyps but) no signs of cancer. Satisfaction with the procedure and gratitude towards the screening program for providing a thorough examination after a positive FIT were commonly expressed. Knowing about other population-based cancer screening programs increased the sense of familiarity with the CRC program and some participants articulated appreciation with the fact that society now prioritized a cancer screening program including men who supposedly were less able to take good care of their health. Many participants emphasized early detection of disease as an optimal way to support effective treatment and found it reassuring to be examined, although the colonoscopy examination itself was unpleasant.

Participation in CRC screening was considered by many a moral and social obligation given that society has devoted scarce resources to it.

#### *4.1.1 Strengths and limitations*

**The variation in the sample was a strength to the study. The 22 participants varied in terms of gender (10 women, 12 men), age (58-74 years), marital status (13 married, 9 single), previous experience with colonoscopies (12), previous visible blood in the stool (15), and polyps (14).**

**Thirteen out of 22 participants were above the retirement age (65 years) (Table 1).**

We conducted semi-structured face-to-face interviews that allowed participants to speak at length within the private sphere and comfort of their homes, rather than using questionnaires or focus groups where participants may feel a pressure to conform to group norms on a sensitive and private topic. The social and moral aspects of screening participation might have been even more evident if discussed in a focus group. By letting our participants elaborate on the topics in the comfort of their homes, we allowed them to speak more freely, also about the moral aspects they considered important.

The fact that the participants had all been interviewed 4-6 weeks before could have encouraged them to recall and align their previously stated expectations with the answers given in this second interview (36). However, our analysis focused on what appeared most important for participants as they reinterpreted their experiences in the (current) interview context, as this phenomenon may also be seen as an attempt to construct a meaningful narrative about the whole screening experience (31, 37).

~~The fact that the experiences of a sample of individuals (with a wide range of medical and social differences, see Table 1) had so many shared features may suggest that the sample was too homogenous to begin with. For instance, there were no apparent differences in the accounts about CRC screening experiences between participants who had polyps removed and those who did not. However, findings from the interviews before the colonoscopy showed variations in experiences, particularly in coping styles (29). This indicates that the individuals were sampled in a satisfactory way, and any lack of extreme cases in this study should not be a sign of inadequate~~

~~information power.~~

The findings in our study may be transferable only to socio-cultural settings characterized by high levels of trust in a healthcare system which is publicly funded by taxation, and a high uptake in CRC screening (38).

#### *4.1.2 Comparison with existing literature*

Trust is essential for medical practice (39-41). It requires a 'leap of faith' under conditions of uncertainty, it is rooted in past experiences about trusting relationships with good outcomes, and it involves positive, flexible expectations of other parties' (persons' or systems') intentions or actions. Thus trust can be developed by routines (familiarity), duration of experiences, shared values, and valued characteristics (42). Two types of trust are at play: interpersonal and institutional trust. Interpersonal trust can be defined as a mutual confidence that no party will exploit another's vulnerability, and an acceptance of the risks associated with the type and depth of the interdependence inherent in a given relationship (43). Interpersonal trust can be developed in face-to-face encounters which involve vulnerability or information asymmetry, dependency, and uncertainty. Institutional trust is trust in systems, organization, professions (e.g. HCPs) which is formed by social expectations of 'regular and honest behavior' (44). Institutional trust is negotiated, reinforced or challenged in social interactions – called 'access points' - between people needing to trust (e.g. patients) and people representing the systems or institutions (e.g. doctors, nurses) (42). In the Danish CRC screening program using FIT, participation relies on institutional trust, since no face-to-face encounters take place with a HCP in the invitational procedure, in the collection of the screening sample, or in the provision of the screening result. It has been suggested that participation in CRC screening using self-sampling requires a larger 'leap of faith' for participants due to deficits in knowledge and lack of familiarity with the procedure, and most importantly a lack of access point, in the shape of a trusted HCP who can mediate between the institution (screening) and the individual (43).

In our study, the screening participant meets an HCP only if he/she attends for follow-up colonoscopy after a positive FIT. In medical encounters, important factors in establishing interpersonal trust include medical competence and skills, respect for patient views, and

information sharing (45, 46). Most participants in our study emphasized the caring behavior of the HCP indicating that HCPs' attention to patient views, patient involvement, and information sharing during the colonoscopy examination were essential in establishing trust in the validity of the colonoscopy result and in future CRC screening. The emphasis on caring behavior could indicate that the participants expected good medical skills and additionally they experienced empathetic skills too. The clinical situation was transparent and involving, despite the fact that patient-HCP communication may traditionally play a minor role in this kind of examination because the patient has little ability to affect the outcome. Trust in the validity of the colonoscopy result was created in this 'access point', in the social interaction in the clinical encounter. The performance of the HCP in the medical encounter might play an important role in the continued trust in the relevance of CRC screening for participants who have experienced a 'false alarm' for CRC (47, 48). The HCPs act as representatives for the health care system (institutions), but how interpersonal trust might apply to institutional trust and vice versa, is unclear (49, 50).

Denmark is renowned for a high level of institutional trust in healthcare services (51-53), and this might play a pivotal role in the high participation rate in Danish CRC screening compared with other high-income countries (43, 54). However, trust in health authority recommendation may not be decisive for people's wishes or choices regarding screening in all cases. People sometimes wish to get screened despite health authority recommendations to refrain from screening (55, 56). Desires for a thorough health investigation may sometimes be a more decisive factor for participation than trust in health authority recommendations – trust is not blind.

Most participants in our study accepted the risk of 'false alarm' as a condition that comes with trust in medicine, medical screening and with wanting to know about one's health in general. After the follow-up colonoscopy, many participants told their family and friends they had been 'acquitted', i.e. screened positive for blood in the stool but cleared for CRC. This indicates that confirmation of good health has a value in itself (57) and may be established as a meaningful narrative with drama and relief, expressed and interpreted in a social context (37, 58). It has been suggested that a 'false alarm' might elicit a feeling of being examined for good, triggering a 'relaxation effect', potentially delaying visits to the doctor in case of emerging symptoms or not participating in future screening (19, 59). Our study indicated that participants' experiences did not hamper intentions for future screening.

Many participants in our study felt that screening participation was a moral and social obligation both from personal, interpersonal and societal perspectives. Cervical and breast cancer screening studies suggest that screening might constitute a moral framework of responsibility and obligation, embedded in social practice because screening is both a medical and a social intervention (40, 60-63). This is supported by surveys in the UK, the US, and Denmark, which show very enthusiastic attitudes to screening, and among people who had previously participated in breast or CRC screening, a majority felt that non-participation in screening is 'irresponsible behavior' (64-66). Thus screening participation is not morally neutral but framed as a benefit for individuals and society in terms of reduced suffering and healthcare costs. It has been argued that socialized healthcare systems often remind residents about scarcity of resources which might appeal to the residents' sense of obligation to participate in screening programs, and which may help explain the high level of CRC screening participation in some countries (22). This may also apply to the Danish context where there are strong notions of individual responsibility to stay healthy and participate actively in the welfare state (67, 68).

#### *4.2 Conclusion*

Perceptions about CRC screening after a non-cancer colonoscopy result were characterized by **trust in the validity of the result, satisfaction with the procedure, and perceived obligation to participate both for themselves and others.**

The study showed that patient involvement and both empathetic and medical skills in the follow-up investigation after a positive screening result are important, in order to support patients' trust in the validity of the non-cancer colonoscopy result. This might be particularly important in screening programs using self-sampling without direct involvement of a HCP at invitation, sampling, or providing results. The study pointed towards some participants' perceived benefits of being awake during the colonoscopy (instead of full sedation), because feeling involved in the examination by watching the display screen with the HPCs supported participants' trust in the validity of the result showing no cancer. Finally, the study indicates that familiarity with screening in general and knowing someone who had participated in other screening programs could increase trust and willingness to engage in active decision-making about screening participation. This



suggests the value of co-ordinating information strategies across different population-based screening programs.

#### *4.3 Implications for practice*

Organizational and behavioral factors that support institutional and interpersonal trust in the medical encounter should be identified and advanced by policymakers and in medical training. In order to build and support patients' trust in the validity of outcomes, HCPs should be particularly attentive to patients' preferences for involvement during colonoscopy and to assess the benefit for the individual patient of using little or no sedation if possible. Information to future invitees after a 'false alarm' experience could build on peoples' trust in the validity of a previous non-cancer result and should underscore the importance of subsequent screening even after a 'false alarm' for cancer.

#### **Abbreviations**

HCP: healthcare professional

CRC: colorectal cancer screening

FIT: fecal immunochemical test

#### **Consent for publication**

All participants gave consent for publication.

#### **Data availability**

Requests for access to data should be addressed to the corresponding author.

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### **Declaration of interests**

None.

### **Authors' contributions**

PK and BA designed the study. PK conducted the data collection and the initial coding was undertaken by PK and BA. PK, BA, and AE were involved in the finalizing work of the analyses, and PK made the final write-up of the manuscript. All authors read and approved the final manuscript.

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**Table 1. Participant characteristics**

\*Married couple. Both had a positive FIT result and had undergone colonoscopy with a negative result for cancer.

Name (pseudonym)	Sex (F=female, M=male)	Age (years)	Marital status (m=married, s=single)	Previous colonoscopy	Previous symptoms: visible blood in the stool / hemorrhoids	Outcome of colonoscopy: polyps / hemorrhoids
<b>Interviews with spouse present</b>						
Judith John (spouse)	F	68	m	yes	yes/yes	no/no
Robert Linda (spouse)	M	60	m m	no	no/no	yes/no
Jane*	F	61	m	no	yes/yes	yes/yes
Mark*	M	61	m	yes	yes/yes	no/yes
Mary *	F	74	m	yes	yes/yes	yes/yes
Peter*	M	74	m	yes	yes/yes	yes/yes
<b>Interview individual</b>						
Richard	M	74	s	no	no/yes	yes/yes
Michael	M	58	m	yes	yes/yes	no/no
Karen	F	60	m	yes	yes/yes	no/yes
Frank	M	67	m	yes	yes/yes	yes/no
Christine	F	70	m	no	no/yes	yes/yes
Connie	F	74	s	no	yes/yes	yes/yes
Thomas	M	58	s	no	yes/yes	yes/yes
William	M	69	s	yes	no/yes	no/no



Joan	F	71	m	yes	yes/yes	no/no
Julie	F	58	s	no	no/no	yes/no
<b>Telephone interviews</b>						
Susan	F	74	s	no	yes/no	no/no
Betty	F	74	s	yes	yes/no	yes/no
Daniel	M	74	s	yes	yes/yes	no/yes
David	M	60	m	yes	yes/no	yes/no
Kenneth	M	58	s	no	no/no	yes/no
Brian	M	59	m	no	no/no	yes/no